U.S. Department of Health and Human Services National Institutes of Health National Heart, Lung, and Blood Institute

National Asthma Education and Prevention Program Coordinating Committee Meeting Summary June 24, 2019

The second meeting of the National Asthma Education and Prevention Program Coordinating Committee (NAEPPCC) took place on Monday, June 24, 2019, from 10:03 a.m. to 11:56 a.m. ET. The meeting was open to the public.

NAEPPCC Co-chairs

James P. Kiley, Ph.D. George A. Mensah, M.D.

NAEPPCC Executive Secretary

Susan Shero, R.N., M.S.

NAEPPCC Members Present

Joseph Kofi Berko, Jr., Ph.D.

Sheila Brown

Anne Mentro Fitzpatrick, Ph.D., R.N.

Lynn B. Gerald, Ph.D.

Fernando Holguin, M.D., M.P.H.

Joy Hsu, M.D.

Elliot Israel, M.D.

Robert F. Lemanske, Jr., M.D.

Kenneth Mendez, M.B.A.

Giselle Sarah Mosnaim, M.D.

Gary S. Rachelefsky, M.D.

Lisa M. Wheatley, M.D., M.P.H.

Juan P. Wisnivesky, M.D., Dr.P.H.

Darryl C. Zeldin, M.D.

NAEPPCC Members Absent

Kurtis S. Elward, M.D.

National Heart, Lung, and Blood Institute (NHLBI) Staff Members Present

Neyal Ammary-Risch, M.P.H.

Cheryl Ann Boyce, Ph.D.

Jennifer Curry, M.P.H.

Michelle Freemer, M.D., M.P.H.

Lenora Johnson, Dr.P.H.

Lucinda Miner, Ph.D.

Mark Parker

Maria Powell, Ph.D.

Kate Reardon

Others in Attendance

Charmayne Anderson, Allergy & Asthma Network Michelle Cloutier, M.D., Connecticut Children's Medical Center

Sanaz Eftekhari, Asthma and Allergy Foundation of America

Tracy Hammond, M.A., Polsinelli

Barbara Kaplan, American Lung Association

Patricia Enright Kaplan, Westat

Kristen LeBaron, M.S., The Scientific Consulting Group, Inc.

Cindy Trubisky, American Lung Association

Paul Tucker, M.Ed., Northside Independent School District

Welcome

NAEPPCC executive secretary Ms. Susan Shero and NAEPPCC co-chairs Drs. James P. Kiley and George A. Mensah welcomed members to NAEPPCC's second meeting. Ms. Shero announced two new committee representatives: Dr. Fernando Holguin of the American Thoracic

Society (ATS); and Mr. Kenneth Mendez of the Asthma and Allergy Foundation of America. Dr. Kiley then reviewed the meeting agenda.

NHLBI Health Education Framework

Dr. Lenora Johnson, director of the NHLBI Office of Science Policy, Engagement, Education, and Communications (OSPEEC), described the OSPEEC mission.

NHLBI's health education approach has evolved from the prior focus on individual, broad-based campaigns designed to increase disease specific awareness among a wide-ranging audience. The current, coordinated approach is designed to ensure adoption of evidence by audiences with the greatest need for this information in partnership with other agencies and organizations. NHLBI focuses its efforts on information needs not addressed by others working in related areas, and it targets both individuals affected by disease and health providers, with an increased emphasis on health and wellness.

The three components of NHLBI's health education program are heart health, lung health, and blood health. In lung health, OSPEEC aims to increase awareness of lung diseases and disorders as well as the understanding that some lung disorders can be prevented, controlled, or treated. OSPEEC is partnering with NAEPPCC to raise awareness of asthma as an ongoing major public health problem, to develop guidelines and supportive materials based on the latest systematic evidence reviews, and to use multiple strategies to enhance implementation and adoption of asthma guidelines.

Discussion

Drs. Mensah and Kiley invited NAEPPCC members to consider participation and leadership of future working groups that could focus on the implementation of the upcoming guidelines updates, based on recommendations from the December 2017 meeting. The Working Groups could be structured to address implementation in children, adults, and communities.

NAEPPCC members noted that a barrier to implementation of asthma guidelines in the past was lack of buy-in from organizations. NHLBI needs to determine how best to form partnerships with organizations that can assist with implementation, possibly by giving these organizations materials and funding to share the guidelines with their members. Dr. Kiley explained that professional societies are likely to accept the content of the guidelines, and most have education and dissemination mechanisms for their members. NHLBI might ask the leaders of these organizations to consider how they might help to implement the updated asthma guidelines. Participation of a wide variety of stakeholders, including professional organizations, would need to be represented on the working groups to assist in the implementation effort.

According to NAEPPCC, the target audience for the updated guidelines will be the primary care community, to encourage implementation of the guidelines. Specialist providers who focus on asthma also will be important to reach. Organizations that represent primary care and specialist providers would be important partners for this effort. Dr. Mensah asked committee members to identify contacts and organizations who can help NHLBI reach these audiences.

Potential Partners. Given that meetings of national organizations are not universally attended, NAEPPCC noted that more primary care providers, nurses, and school nurses may be reached through local and regional organizations and meetings. In addition, it was noted that not all schools have nurses, so alternative means of reaching local stakeholders may be needed.

Other potential partners to reach children include:

- Regional organizations for teachers and school resource officers
- Local chapters of national organizations
- School-Based Health Alliance
- County school superintendents, education departments, and health departments

Potential partners for reaching adults, or adults and children, include:

- The Environmental Protection Agency (regional representatives)
- The Centers for Disease Control and Prevention (CDC)
 - CDC's National Asthma Control Program has partnerships with 25 state health departments and nongovernmental organizations that serve children and adults. The new cycle of grants will start in the fall of 2019.
- Housing agencies, because home environments play an important role in asthma
- Community organizations, medical centers, and religious organizations, for reaching older adults
- Pharmaceutical companies
- Congressional committees involved in health care
- Third-party payers, which play an increasingly important role in driving health care
- National organizations with an interest in asthma, for example:
 - o American Academy of Allergy, Asthma, & Immunology
 - o Asthma and Allergy Foundation of America, which can help provide patient input into message development and dissemination
 - o American Lung Association, which can amplify messages about the updated guidelines and provide the patient voice for dissemination and implementation
- Electronic medical record developers, to integrate asthma guideline information at the point of care without interfering with providers' workflow

Partners that can reach communities include community health workers, asthma educators, and social networks.

Messaging. In response to an NAEPPCC question, Dr. Johnson clarified that OSPEEC will assist in developing materials for the target audiences of the revised guidelines. OSPEEC works closely with scientific experts to develop materials on health topics, including asthma (see https://www.nhlbi.nih.gov/health-topics/asthma). OSPEEC's materials are publicly available and can be modified when needed for specific audiences.

OSPEEC's responsibilities also include engaging with policymakers. Based on their interest, OSPEEC will inform members of Congress about the updates to the asthma guidelines, allowing them to disseminate as appropriate. OSPEEC will leverage digital and traditional media to spread

information as widely as possible, based on its experience using a variety of media activities in health education programs.

NAEPPCC made several comments on factors to consider that may affect implementation of the updates to the guidelines:

- Messages should be easy to understand for any patient audience, including those with cognitive impairment, limited health literacy, or comorbidities.
- Messages for primary care providers, especially those whose patients are older adults with numerous comorbidities, must be easy to integrate in the course of care.
- Messages should be straightforward, with additional information available for those who want more information.
- Given providers juggle competing demands, messages should guide them in integrating recommendations with other responsibilities.
- Guidelines must be patient-centered.
 - o Dr. Johnson said that OSPEEC works with patient advocacy organizations to identify needs and to develop and test messages and materials.
 - Dr. Michelle Cloutier, who chairs the NAEPPCC working group that is updating
 the asthma guidelines, said that the working group does not have any patient
 representatives, but it does take patient preferences and patient burden
 into account.
 - Dr. Kiley added that patients will have an opportunity to submit feedback on the draft asthma guidelines when they are issued for public comment, and NHLBI will reach out to patient advocacy groups to inform them of this opportunity.

The ATS Documents Development and Implementation Committee has experience developing this type of messaging. Dr. Holguin offered to find the names of organizations that work with the ATS committees to disseminate clinical guidelines. Additional offers to assist came from representatives from the American Lung Association and the Asthma and Allergy Foundation of America (Mr. Mendez).

NAEPPCC Working Groups. NAEPPCC members and other stakeholders are welcome to join the committee's working groups. The following individuals volunteered to join the three future working groups—on adults, children, and communities:

- Working group on adults: Dr. Holguin, Dr. Elliott Israel, and Dr. Juan P. Wisnivesky
- All three working groups: Dr. Joseph Kofi Berko, Mr. Mendez, Dr. Giselle Sarah Mosnaim, and Ms. Cindy Trubisky

NHLBI will appoint co-chairs for each working group and will ask the remaining NAEPPCC members to volunteer to serve on one of these groups. Committee members are welcome to invite other stakeholders to join these groups as well.

Update on Asthma Guidelines

Dr. Cloutier reported that the NAEPPCC Guidelines Working Group includes allergists, pulmonologists, pediatricians, and family and internal medicine providers. Members have

expertise in implementation research and clinical decision support. The working group's charges are to:

- Use the Agency for Healthcare Research and Quality's systematic reviews to update selected topics identified through a needs assessment.
- Draft new clinical recommendations for these topics and grade the strength of each one.
- Consider implications for guideline implementation while drafting recommendations.

Based on a needs assessment and community feedback, the working group is updating the guidelines for the following six topics:

- Intermittent inhaled corticosteroids
- Long-acting muscarinic antagonist therapy
- Bronchial thermoplasty
- Immunotherapy
- Indoor allergen reduction
- Fractional exhaled nitric oxide

The working group uses the GRADE (grading of recommendations, assessment, development, and evaluations) approach to assess the certainty of the evidence from very low to high, to develop clinical practice recommendations, and to assess the strength of these recommendations.

The working group plans to issue its draft recommendations for public comment and review by NAEPPCC and federal partners between December 2019 and January 2020. After federal approval, the Update on Selected Topics is expected to be published in the fall of 2020. In addition to the full report, the working group plans to publish its recommendations in a peer-reviewed journal and develop a one-page infographic for the NHLBI website.

Discussion

NAEPPCC suggested that the working group find ways to include patients in its deliberations, beyond asking them to review the draft guidelines during the public comment period. Dr. Cloutier said that several working group members have contacts with large groups of patients, and it is not too late to engage patients in the process. One potentially richer and more informative approach might be to bring the draft guidelines to groups of community members and to help them understand the process for developing the guidelines and their implications. The working group has examined the literature on patient preferences, which are not always consistent with clinician preferences. Mr. Mendez offered to provide patient perspectives and preferences to the working group.

Another NAEPPCC recommendation was to develop easy-to-read digital images. Many community providers might not have access to the journal that publishes the final guidelines, and infographics and social media could be powerful ways to disseminate the guidelines. Dr. Cloutier agreed, noting that the approaches Dr. Johnson mentioned would help ensure that the guidelines are user-friendly and can be integrated into the context of care.

Review of Action Items and Wrap-Up

Dr. Kiley summarized the meeting discussions. Dr. Johnson had described OSPEEC's new approaches to health education that will leverage new technologies to educate different audiences about health, wellness, and disease. The discussion of her presentation focused on implementing the updated asthma guidelines, which is a major effort for the committee. NAEPPCC also received an update on the activities of the Expert Panel Working Group, which is making good progress. NHLBI heard the committee's emphasis on the need to integrate the patient voice into the recommendation development process, and the Institute will address this need.

On behalf of NHLBI, Dr. Mensah thanked NAEPPCC and Dr. Cloutier for their participation in this meeting. Some of the recommendations from this meeting include the following:

- Partner with stakeholders regarding the updates on selected topics in the asthma guidelines, including general as well as specialty professional societies, local and regional organizations (including federal agencies with local representatives), and others with an interest in asthma care that can disseminate the new recommendations to a broad range of audiences.
- Leverage relationships, such as those between CDC and state health departments, as well as the relationships of ATS, the American Lung Association, and the Asthma and Allergy Foundation of America.
- Find ways to capture the patient perspective in the recommendations development
- Consider the importance of the environment (such as housing).
- Develop tools that leverage existing technology to facilitate integration with patient care and daily life (e.g., decision support tools, electronic health records, apps).

The meeting was adjourned at 11:56 a.m.

Certification

I hereby certify that the foregoing minutes are accurate and complete.

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Susan Shero, R.N., M.S.

NAEPPCC Executive Secretary

James P. Kiley, Ph.D.

NAEPPCC Co-Chair

George A. Mensah, M.D.

NAEPPCC Co-Chair